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ABSTRACT

The Young Adult Institute (YAI), a private, nonprofit agency serving developmentally disabled persons in the New York City metropolitan area, designed and implemented a program which used a videotape and detailed staff training manual to teach clients how better to protect themselves from contracting acquired immune deficiency syndrome (AIDS). The protection program was targeted in particular to higher functioning clients who participated in community activities on a more independent basis and received less supervision than did more severely disabled clients. The following program objectives were identified: (1) define AIDS, and state why it is so dangerous; (2) state who is at risk for contracting AIDS and how it is contracted; (3) identify risky sexual practices; (4) identify safer sexual behaviors and practices; (5) teach clients how to resist social pressures that may lead to risky or unsafe sex; and (6) demonstrate via videotape the use of a condom. Possible dilemmas regarding AIDS training, such as parental objections, are noted. Among four policy statements regarding AIDS education are that all clients deemed at risk must receive specific AIDS training taught at their cognitive level. (JW)

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AIDS - Teaching Persons With Disabilities to Better Protect Themselves

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ABSTRACT

AIDS is rapidly spreading through our society in almost epidemic proportions. It would be naive to think that people with mental retardation/developmental disabilities are not susceptible to AIDS. The authors have written an article about a training program designed specifically for people with developmental disabilities. This program which includes a videotape and manual teaches these clients to better protect themselves from this deadly disease. Outcomes from the program clearly demonstrate the ability people with mental retardation and developmental disabilities to understand the problem and learn to better protect themselves. Dilemmas and policies for both state systems and private agencies are also delineated.

The United States Department of Health and Human Services has identified AIDS, Acquired Immune Deficiency Syndrome, as an epidemic which is rapidly spreading through all facets of our society. In order to prevent/minimize the spread and effects of this devastating disease, the Surgeon General has clearly stated that "education concerning AIDS must start at the lowest grade possible as part of any health and hygiene program... There is no doubt that we need sex education in schools. The threat of AIDS should be sufficient to permit a sex education curriculum with a heavy emphasis on the prevention of AIDS and other sexually transmitted diseases." (1987, pg. 31).

Persons with mental retardation/developmental disabilities are often overlooked when identifying people in our society who are susceptible to AIDS. These individuals, representing approximately 3% of the total U.S. population are now, as a result of the success of the deinstitutionalization and normalization movement, living, functioning, and becoming more fully integrated into their communities. It is estimated that approximately 90% of all individuals with mental retardation/developmental disabilities function within the mild/moderate range of disability. Concomitant with the benefits of integration and increased participation in the community,

arises a degree of risk due to the individual's possible impaired judgment. Trained professionals in the field have a responsibility to ensure that clients receive the appropriate level of education in regard to methods to reduce the likelihood of their contracting AIDS. The Village Voice, October 20, 1987 cited approximately 40 cases nationwide of AIDS among people with developmental disabilities, 8 of whom are in the New York City area. There is no question that our clients are susceptible, and that given their communal living arrangements, they could rapidly spread AIDS among themselves. (pg 12).

The philosophy of the Young Adult Institute (YAI), a private, not-for-profit agency serving 1500 people of all ages and functioning levels on a daily basis through over 50 programs in the New York Metropolitan Area, assumes a proactive posture in addressing the needs of persons with mental retardation/ developmental disabilities. Anticipating client needs regarding AIDS training becomes critical due to the terminal nature of the disease, and the geographic distribution of reported AIDS cases. "As of November, 1986, in the United States, there have been more than 26,500 cases of AIDS reported to the Centers for Disease Control over a six year period, with a steady increase each year since the identification of the disease in 1981. 32% of the cases in the United States reported are from New York State. More than 8,500 New Yorkers have been diagnosed with AIDS as of October 20, 1986, with nearly 90% of these cases having been

reported from New York City." (Acquired Immune Deficiency Syndrome, pg. 6).3 It is important to note that while the epidemic is most highly concentrated in New York and California at the current time, it is definitely a national issue, and by no means confined to only two areas.

In a memorandum issued from the New York State Office of Mental Retardation/Developmental Disabilities on September 8, 1986, guidelines for management of Acquired Immune Deficiency Syndrome and related conditions were issued. The memorandum stated that "each facility is to develop a mechanism for assuring that training and policies and procedures for the management of AIDS are developed and implemented. Education of staff should commence at once to prevent alarm or staff's overreaction, should a staff member or client develop the disease."

In reviewing the training curricula available throughout the country, YAI discovered an apparent paucity of materials regarding training of persons with developmental disabilities vis-a-vis AIDS. Our experience demonstrates that training programs, which are to be implemented directly with clients, need to be designed to communicate in concise, clear language which individuals can easily understand. The New York City Department of Health has clearly stated the need for AIDS education for young people in school. "It is important that young people

receive sex education, including AIDS education, at home and in school. Such educational efforts can make a difference, as evidenced by the 80% reduction in the rate of sexually transmitted diseases gained by men in the New York City area in the last several years" (AIDS: A Special Report on Acquired Immune Deficiency Syndrome, p. 19).[4] People who are mentally retarded, likewise, need an educational program, especially one that is geared to their level of comprehension.

CHALLENGES TO AN AGENCY WHEN DESIGNING A PROGRAM TO PREVENT THE ACQUISITION OF AIDS

I. Should an agency require AIDS training for its clients?

The prevention of AIDS is a very complex process that offers many alternatives to organizations that serve persons with mental retardation. One alternative is to do nothing. An agency might take no action because there is an inherent fear that this is a highly charged issue, or because:

A. They may not believe that clients will contract AIDS because they do not believe that the clients are vulnerable or even engaging in sexual activities.

B. An agency might be afraide of parent reaction in educating the client.

C. There might also be some underlying moral beliefs that would preclude teaching about AIDS.

At YAI, we believe that alternatives to AIDS education are no longer acceptable, because the ultimate alternative is death. As indicated by the Surgeon General, there must be AIDS education. We can no longer moralize or procrastinate while the disease is rapidly spreading.

II. How does an agency begin to build a protective system for its clients?

In December of 1985, YAI decided to organize an AIDS Task Force to fully explore the issue of AIDS and see if any action on our agency's part was warranted to protect our clients. In considering the composition of the Task Force, we decided to pool different types of people from various positions. This would ensure that the Task Force was a true composite of all concerned parties, and that all parties would be heard. The Task Force consisted of both homosexual and heterosexual men and women who are clinicians, trainers, direct care staff and management staff. Through the input of the Tssk Force, we quickly learned that we knew very little about the disease and had many misconceptions. We also began to realize that information regarding the spread

of the disease kept changing rapidly and that we needed to stay current on how the disease was tranmitted. We decided on the following goals for the Task Force:

A. To explore the issue of AIDS in depth and identify what we need to know and what we can do to prevent this deadly disease from spreading to our clients.

B. To develop and implement a comprehensive AIDS education program for clients who are mentally retarded and the team working with them.

C. To disseminate our findings to all agencies that serve people who are mentally retarded so as to enable them to provide for the AIDS education/protection needs of clients whom they serve.

Recognizing our limited knowledge of the disease, we requested and were provided with a consultant from the Department of Health in New York City. This consultant provided greatly increased knowledge of the disease and, when combined with YAI's expertise in the field of developmental disabilities, permitted the formation of an AIDS Task Force capable of developing a protective program.

III. Designing a program to teach people who are mentally retarded to better protect themselves.

In designing a protection program against AIDS for people with mental retardation, we needed to identify which clients required immediate training and education. Many of our clients who are mild/moderately retarded utilize the community independently to a much greater degree than do those people who are severely/profoundly retarded and receive far more supervision. They also have more opportunities for sexual contact in the community than those individuals who are severely handicapped. Consequently, we decided to design our initial training for this higher functioning, more independent, population.

We also debated what we could realistically teach our clients regarding changing their sexual lifestyles. Should we teach them that having multiple partners is not okay? That kissing may spread the virus? Through the guidance of our consultant from the Deaprtment of Mental Health, we learned that the most important preventative measure is to wear a condom. Abstinence is one viable option for people to choose and we would support a client's decision to abstain from sex. However, for many of our clients, that would not be a realistic lifestyle decision. While it is

advisable for individuals to reduce the number of their sexual partners, the latest information indicates that you can contract the disease from one partner or from many partners if you are not protected. Therefore, to reduce the likelihood of clients becoming confused, we decided to teach them that no matter whom you are with, the male(s) must always be wearing a condom. We realized that our clients wer not intravenous drug users, so we focused only on the sexual transmission of this disease.

IV. <u>How explicit should the training be when teaching our clients protective measures?</u>

Any training designed for people who are mentally retarded needs to be constructed in a manner that enables them to learn, compensating for their impaired cognitive development. There is no question that our clients learn best through a concrete, multi-sensory approach and we, therefore, designed a training tape to enhance their understanding of the problem through visual and auditory instruction. The Task Force explored the most concrete methods possible to ensure that our clients would learn about and, therefore, utilize condoms. We also were concerned about how explicit our training should be when teaching our clients. Given the deadly nature of the disease, YAI decided that we must be as explicit as

necessary in our training while remaining highly professional and discreet in order to ensure that our clients fully understand how to better protect themselves. This was not easily achievable, considering the subject matter, but was carefully weighted in the production of all materials and was ultimately, in our opinion, ensured. Hence, in our training tape, we show scenes of sexual activity with condoms being utilized. During the training we asked clients to state why these people were better protected. We also clearly stated that the only certain way of staying safe from AIDS is to abstain or to masturbate. Using a condom is safer than other forms of protection, but not absolutely safe. We are not encouraging sexual acts through our training; rather, this tape is designed to help stop the spread of AIDS through safer sex for those consenting adults who choose to be sexually active.

V. <u>What objectives should be included in an AIDS training program for people who are mentally retarded?</u>

The AIDS Training Committee at the Young Adult Institute designed a staff training manual to assist trainers in teaching the clients about the nature of AIDS and its prevention. Included in this manual are very specific teacher instructions, teacher statements, and teacher questions. We require our teachers to instruct according to

the manual almost verbatim, utilizing the teacher statements and questions.

After long discussions, we decided that the objectives for this manual and the subsequent training be designed to ensure that our clients will be able to:

A. Define AIDS, and state why it is so dangerous.
B. State who is at risk of contracting AIDS and how it is contracted.
C. State what is risky and unsafe sex.
D. State methods of safer sexual practice(s).
E. State how they will resist social pressures that may lead them to engage in risky or unsafe sex.
F. For all clients, demonstrate, in the most appropriate manner (typically through the use of anatomical models), the use of a condom, including how to put a condom on and how to take a condom off.

Included in the manual is an extensive follow-up system to ensure that clients are fully protected. We realize that a one session training provides the basic principles and teaches the most important points, but substantial individual counseling is also needed. All clients who are considered at risk will participate in both the initial educational training program and the follow-up training/counseling system at their program.

OUTCOMES FROM AIDS PROTECTION PROGRAM

At the Young Adult Institute, we targeted our AIDS protection program to those clients who seem most at risk. These higher functioning clients lived in 10 of our 20 community residences, and participated in our employment and socialization programs. Currently, approximately 200 people with mental retardation and developmental disabilities have received this training. At present, we have not empirically studied the full effects of the training program. This study will be implemented through an empirical model in the near future. We decided that due to the nature of the disease, and its rapid spread in the New York City area, to begin the training as soon as possible. Based on these initial trainings, we were able to observe the following:

1. Many of the clients have heard of the word AIDS and do know that it is some form of disease. However, they were not aware of its deadly nature and were very concerned that people are dying from AIDS. We realized that some of our clients will be frightened by this knowledge. However, most people in our society are frightened and part of this scare is healthy as long as it is not irrational. We quickly explained to the clients that if you learn to better protect yourself, you don't need to be as afraid. That message seemed to reassure them that they can, indeed, take care of

themselves.

2. Generally, many of the clients indicated that if you stay clean, take regular showers, wash your hands, etc., you would not be susceptible to contracting AIDS. Through scenes on the video and discussion as defined in the manual, the clients learned while cleanliness is important, merely staying clean will not protect you from contracting AIDS. We strongly emphasize the issue of sexual transmissions through blood, semen and vaginal secretions. Most of the clients were able to list these three fluids as a conduit of AIDS after receiving this section of the traininhg. Also, a good number of the clients throught that they were not susceptible to contracting AIDS before the training. Subsequently, they stated that everyone is susceptible to the disease.

3. In discussing the issue of safer sexual practices, many clients were surprised to find that such sexual acts as oral or anal sex can spread the disease. A number of clients stated that they were surpirsed that one can contract AIDS through a various number of sexual acts. The use of three graphic pictures on the film greatly enhanced the clients' ability to understand that they must always wear a condom if they are having sex with another person. A great area of concern for the AIDS committee was the problems clients were

having putting ocndoms on the anatomical models during the training. If the clients could not learn to put a condom on themselves or someone else, then the trianing would ultimately not be effective. Initially, we taught the clients to put a condom on through a total task procedure, but found it necessary to break the skill of putting on a condom into six distinct steps. Still, there were a number of clients who needed much more practice. This was noted in the follow-up sheet that is distributed to the program. The program was instructed to provide further training to these clients.

4. When we first began our training, we had men and women in the same group. We noted that the women were very hesitant to practice putting the condom on the model in front of the men. They also seemed to be rather shy and did not fully participate in the discussions. When we separated the women and men in groups, the results were startling. They related that their biggest concern was feeling pressured by men to engage in sex without a condom. A videotape scene in the AIDS film shows a woman resisting this pressure. This is a dilemma faced by many women in our society, but is particularly acute for a woman who is mentally retarded/ developmentally disabled. The availability of a peer group for many of our clients is quite limited, and when they do have a boyfriend, they are easily susceptible to "emotional

blackmail." The discussions that ensued based on the videotape scene proved to be quite emotionally charged, and allowed them to fully vent some of these feelings. Many of the women appeared quite resolute based on the peer support that their partner must wear a condom so that they can be protected.

The men, for the most part, realized the importance of wearing a condom and stated that they will protect themselves because they do not want to die from AIDS. A few of the men resisted because they did not like to wear condoms and these issues needed to be resolved in further training in the programs.

Overall, our clients appear to greatly benefit from the straight forward and explicit nature of the training. We believe that, due to the adult manner in which the material was presented, our clients have acted accordingly as mature adults. Our programs have reported that our cleints are indeed using condoms and we have initiated follow-up systems for those clients who need further training. The exactness of the training manual and the availability of the training videotape have ensured that all of our clients have received appropriately structured, consistent, and well informed AIDS protection training.

In our discussions with various agencies, professionals, parents, and clients, a number of dilemmas evolved. These frequently raised, and by no means simple, questions are listed below, along with what we feel are the most appropriate answers given the deadly nature of the disease.

DILEMMAS REGARDING AIDS TRAINING AND POSSIBLE ANSWERS

Q. WHAT IF PARENTS OBJECT TO AIDS EDUCATION?

A. Parental objections to AIDS education are no longer acceptable for clients in our programs for whom we have accepted responsibility. Any given client can infect many other clients. Since AIDS kills, all of our clients must receive AIDS education. Our responsibility is to all of our clients and one client can impact on all the others.

Q. SHOULD WE USE EXPLICIT SEXUAL SCENES IN TRAINING OUR CLIENTS?

A. In order to fully protect our clients, we must not take anything for granted, including their ability to understand what we are teaching. We are not encouraging them to engage in any sexual activity, but rather teaching them how to prevent their catching this deadly disease should they choose to engage in sexual activity. All efforts are made

to be as discreet and professional as possible.

Q. SHOULD WE STOP OUR CLIENTS FROM USING PROSTITUTES?

A. The use of prostitute by anyone is not acceptable because it is illegal. A particular dilemma has arisen because our clients sometimes do not have the opportunity to meet people with whom they can develop a loving and sexual relationship. Consequently, a small number of clients have utilized prostitutes. Prostitution can cause physiological and psychological harm. Especially given the AIDS epidemic, we are constantly looking for innovative ways to help them to meet people with whom they might form a meaningful relationship.

Q. SHOULD WE MAKE CONDOMS AVAILABLE?

A. YAI now makes available the recommended condoms at every appropriate program for our clients.

Q. SHOULD WE CONTROL A PERSON'S LIFESTYLE IF HE/SHE CANNOT BE PROTECTED FROM AIDS, ESPECIALLY IF HE/SHE IS MENTALLY RETAREDED?

A. We are very sensitive to a client's rights and do not want to control anyone's lifestyle. However, given any serious

health and safety concern, especially AIDS, we must intervene when required. Through the education process, we hope that clients will fully understand the seriousness of the disease and take the appropriate steps to protect themselves. However, if a client does not demonstrate the ability, willingness, or comprehension to take these steps, then we will set firm limits with them until they can demonstrate appropriate behaviors to ensure their health and safety.

GOVERNMENTAL POLICIES NEEDED TO HELP PEOPLE WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES BETTER PROTECT THEMSELVES FROM AIDS

In assisting governmental agencies in writing policies regarding AIDS, the following two assumptions need to be delineated first then followed by three policy statements.

ASSUMPTION 1:

Recognize that people with mental retardation/developmental disabilities are sexual human beings and are susceptible, like anyone else, to the AIDS virus if they practice unsafe sexual activities.

ASSUMPTION 2:

Because of the communal residential living environments within which many people with MR/DD currently reside, the AIDS virus can rapidly be spread. Therefore, action must be taken immediately to educate and train all clients who are deemed at risk.

POLICY STATEMENT 1:

All staff should receive AIDS education so that our clients receive the proper information regarding this disease, and that the staff will not panic if one of their clients is infected with the AIDS virus.

POLICY STATEMENT 2:

All clients deemed at risk must receive specific AIDS training taught at their cognitive level. The training program must ensure that the clients can utilize the proper methods to better protect themselves, (i.e. condoms).

POLICY STATEMENT 3:

All clients who are sexually active need to be protected from AIDS and must have accessibility to recommended condoms.

POLICY STATEMENT 4:

All clients who are deemed at risk and choose to abstain from sexual activity with another person should be reinforced for that behavior.

SUMMARY

"AIDS is a life threatening disease and a major health issue. It's impact on our society is and will continue to be devastating. By the end of 1991, an estimated 270,000 cases of AIDS will have occurred with 179,000 deaths within the decade since the disease was first recognized. In the year 1991, an estimated 145,000 patients with AIDS will need help and supportive services at a total cost of between $8,000,000,000 and $16,000,000,000. However, AIDS is preventable. It can be controlled by changes in personal behavior." (Surgeon General's Report, p. 7).[5]

As professionals in the field of mental retardation, we must ensure that clients receive the trianing needed so that they will not contract and transmit this disease. The epidemic is rapidly spreading and it would be naive to think that persons with developmental disabilitie will not be affected. At YAI, we are proceeding as rapidly as possible to provide the best education

program for our clients. All agencies must take the initiative to educate and train the people for whom they have assumed the responsibility of oversight and protecting. There is no alternative to AIDS education. The likely alternative is death.

We wish to express our acknowledgment and appreciation to the YAI AIDS Task Force: Daryl Shapiro, Jules Feiman, Tom Ott, Frank Olcvary, and Barry Lace who worked so diligently on this project. Additionally, special thanks to our expert consultant, Rebecca Porper from the New York City Department of Health.

FOOTNOTES

1. Surgeon General's Report on AIDS from the U.S. Department of Health & Human Services, October 22, 1986, pg 31.

2. Village Voice, October 22, 1986, pg 12, Safe Sex Made Simple, Kramer, Louise.

3. Acquired Immune Deficiency Syndrome, 100 Questions and Answers, The New York State Department of Health, November 1, 1986, pg 6.

4. AIDS: A SPECIAL REPORT on Acquired Immune Deficiency Syndrome, revised 1986, prepared for New York City Schools, from The Department of Health, New York City, pg 19.